

September 10, 2012

Illinois Health Care Reform Implementation Council

RE: Recommendations on Establishing an Essential Health Benefits Package (EHB)

Dear Members of the HCRIC:

The Leukemia & Lymphoma Society (LLS) appreciates the opportunity to submit our recommendations on defining the Essential Health Benefits (EHB) package for the State of Illinois. LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services. The mission of LLS is to cure leukemia, lymphoma, Hodgkin's disease and myeloma and improve the quality of life of patients and their families.

The Leukemia & Lymphoma Society (LLS) is committed to ensuring access to and compliance with the most appropriate, evidence-based treatments for all blood cancer patients. Treating cancer involves accessing a complex and extensive set of health care services including chemotherapy and prescription drugs, among others. Unless policymakers provide affordable access to comprehensive care, the promise of the Affordable Care Act will not become a reality for cancer patients or survivors. If a state's Essential Health Benefits (EHB) package leans too heavily toward maximizing flexibility at the expense of ensuring access to comprehensive and quality cancer care, cancer patients may find themselves having insurance that is inadequate to meet their health care needs, while being saddled with crippling financial responsibility for their care.

Blood cancer patients and survivors who are currently uninsured and underinsured, are among those who stand to benefit greatly from the establishment of the state's Health Exchange. Illinois has demonstrated its commitment to cancer patients by enacting legislation that improves the care of cancer patients. One of the most important next steps for the state is to establish a comprehensive Essential Health Benefits (EHB) package of health care services for the exchange; the EHB will also serve as a benchmark for the state's Medicaid program and other insurance coverage available to people in Illinois.

LLS believes that Illinois must take a comprehensive approach when setting the standard for the state's EHB package. To that end, attached please find a set of recommendations that we have developed with the goal of ensuring access, quality and affordability for blood cancer patients in Illinois's EHB package. These recommendations focus on three key principles:

- 1. A meaningful prescription drug benefit that is comprehensive, affordable and enables access to the most effective drug therapies tailored to the patient's needs
- 2. Access to specialists, procedures and technologies for needed diagnostic and treatment services
- 3. Coverage for comprehensive cancer planning as well as palliative and end of life care

We greatly appreciate your consideration of our recommendations. We would welcome the opportunity to meet with you to discuss our recommendations further, as they relate to the benchmark plan options that are currently under review. I can be reached directly at 202-408-7631.

Sincerely,

Brian M. Rosen

Vice President, Legislative & Regulatory Affairs

The Leukemia & Lymphoma Society

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The Leukemia & Lymphoma Society (LLS) strongly urges that Illinois's benchmark plan include the following:

- Prescription drug benefit with full coverage of the six protected classes, inclusion of
 multiple drugs in a range of therapeutic categories, as defined in the Medicare Part D
 program and a patient appeals process.
- 2. Independent Pharmacy and Therapeutic (P&T) Committees that review the drugs included on a Plan's formularies, as well as the utilization management requirements for such drugs, and consideration of newly approved treatments and indications for inclusion in formularies within certain timeframes such as those required under Part D.
- 3. A mechanism for incorporating new therapeutic categories or classes in order to protect patients' access to innovative therapies as they become available.
- 4. Equal treatment of out-of-pocket expense to patients receiving intravenous, injectable, and/or orally administered anti-cancer therapies.
- 5. Drugs and biologics, both physician & self-administered and off-label uses, according to the evidence-based standards utilized in the Medicare program.
- 6. Affordable access to procedures standard to the treatment of blood cancers including bone marrow, blood stem cell, cord blood transplants and radiation therapy.
- 7. Allows cancer patients to seek treatment at National Cancer Institute (NCI) Cancer Centers or any other out of network provider.
- 8. An external appeals process for cancer patients denied coverage of "routine patient care" in cancer clinical trials until the federal requirement for coverage of routine patient care in clinical trials takes effect in 2014.
- 9. Diagnostic services using all available evidence-based technologies.
- 10. Individual, comprehensive cancer planning that is communicated by health care professionals both orally & in written form.
- 11. Palliative & hospice care.

For more information, please contact Brian Rosen, Vice President, Legislative & Regulatory Affairs for LLS at brian.rosen@lls.org